

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

Bill Drake

## **QUESTIONS ANSWERED:**

### **Q1**

#### **ANSWER:**

Social isolation in society generally, and in the family home where the carer lacks the ability to communicate normally with their charge. The sheer mental and physical demand of managing a partner who lacks the ability to cooperate and in some cases actively refuses to cooperate. The lack of appropriate, timely and affordable support from both statutory and commercial care services. The lack of support and understanding in communities in general due in part to fear and lack of information.

### **Q2**

#### **ANSWER:**

A regular complaint arises in hospitals and care homes when patients who cannot complain or explain their problems are given food they cannot eat or feed themselves with, or are left in a soiled condition for long periods. They are often left unattended and lack the means or capacity to call for assistance. Dementia patients are likely to need mental and physical stimulation tailored to their ability or past interests, and this is rarely provided.

### **Q3**

#### **ANSWER:**

Yes they do . Within the majority white Caucasian community it is particularly noticeable that male carers avoid or are resistant to bringing their wives to a communal support group. Male patients appear to show more difficult challenging behaviour and this leads to their exclusion from support groups and Day Centres. The availability of male social groups/clubs to which male patients might find an interest is much lower than that for females who often continue comfortably to belong to Womens Institutes, Mothers Unions etc. The ability of different social groups to mix beneficially in a support setting is hampered by the different levels of education and experience.

### **Q4**

#### **ANSWER:**

I have little experience of this issue but a primary concern will certainly be language and accent which can and does lead to misunderstanding by patient and carer. In the context of medical diagnosis it is clear that the standard tests

for memory loss are flawed if the questions and answers are misunderstood by participants. Many elderly persons as Carers and Patients are stressed in the company of other ethnic groups.

#### **Q5**

##### **ANSWER:**

It is difficult to know how far science has progressed when claims are made in the media at regular intervals. Currently I have seen suggestions that an early screening test may give an indication of probability of developing Alzheimer's. If correct then the benefit would be twofold, firstly to design a cure, secondly to forewarn patients so that they can make lifestyle decisions. The recent report about the curative effect of the arthritis drug "Etanocept". This needs urgent examination.

#### **Q6**

##### **ANSWER:**

Despite the fear generated by early diagnosis, it is desirable that patients are fully informed at the earliest time possible, so that they and their family can make adjustments to their lives and learn to accept the inevitable while the patient still has capacity to make decisions. However the communication needs to be conducted with logic and sensitivity, and this is presently often not the case. Equally the communication should not be a one off interview but a progressive exercise over a period so that the adjustment is a natural development in which patient and carer begin to accept change and the services that can help them

#### **Question**

**8**

##### **ANSWER:**

Essentially the carer has insufficient time and training to respond to those who are difficult and those with greatest difficulty are considered a problem rather than a challenge.

#### **Q9**

##### **ANSWER:**

Yes , I have given examples of good practice in a preceding question. It seems to be largely a question of whether the patient concerned has past affinity to some communal activity, and both the patient and the community can be persuaded to maintain a link. Remember that the resistance to inclusion is just as common by the patient who wishes not to be embarrassed by their weakness. Males are particularly prone to resistance, and it is important that any introduction of patients to a new communal activity is carried out early and is sensitive to the

past experience and lifestyle of the patient.

#### **Q7**

##### **ANSWER:**

Dementia is a cause of fear and embarrassment, certainly to patient and carers, but also to the general public who are often not able to understand the condition and how to respond. It is regrettable that much of the public awareness comes from publicity given to cases of the bad treatment given to dementia patients in hospitals and care homes, and it would help if alternatively good examples were shown of patients who despite their lower mental capacity were stimulated and happy, and the methods of achievement of this stimulated condition e.g. music and singing, simple craftwork, friendship. However it is vital that training of staff at all levels is improved massively and that they are able actively to participate in stimulation and thus see the benefits. Similarly members of the public must be encouraged by example to be inclusive and empathetic when meeting dementia patients. Sympathy is not required-empathy is. I have personal experience of how my wife with severe dementia was never happier than at the local Womens Institute, at a Lace Group, and at Church and this did not take training.

#### **Q10**

##### **ANSWER:**

Yes it follows from the previous answer, that care should be fitted to the patient and not the reverse. However there are practical considerations e.g. where a day centre is obliged by staffing and minimum patient numbers to offer a common programme for male and female patients. Do not expect too many males however to do flower arranging! It would in principle be quite wrong to close the Day Centre because not everyone wished to do all the activities.

#### **Q11**

##### **ANSWER:**

I do not think a persons identity is changed, but that pre-existing characteristics are enhanced or suppressed. Thus often if certain inhibitions imposed by society or training are removed by the loss of capacity then these are identified as changing the identity.

#### **Q12**

##### **ANSWER:**

The changes can be both distressing and physically dangerous to a carer, to the point where the relationship fails. In one instance to my knowledge a carer planned to kill her husband having suffered from constant demands and complaining. At the least carers need help, advice and respite when this arises, but this situation is rarely noticed or complained about by carers to professionals.

### Q15

#### ANSWER:

1. If the patient has capacity and will better maintain or improve the quality of life then life-sustaining treatment should be given 2.If the treatment itself will/may lead to further lowering of capacity, confusion, pain, restriction of movement then treatment should only be given with the consent of an informed and responsible next of kin. This particularly applies where the treatment may involve the use of general anaesthetic and anti-psychotic drugs 3.Advance directives/ Living Wills should always be honoured 4.All patients with Dementia must be clearly identified on admission for treatment of any kind, and Extra-care measures put in place to manage feeding and hygiene, safe movement.

### Q13

#### ANSWER:

With practicality and commonsense. The existence of a Living Will or Advance Directive must be "a priori" the most certain and reliable indication on which to base a critical decision. However it is assumed that low capacity does not prevent a person from signifying their wishes by some means and therefore these wishes should be respected even if that is counter to previous wishes or experience that are not formalised in writing. Only close family or persons with long experience of the patient are in a position to judge the correct decision. Decisions should avoid, if possible, distress caused by a refusal to allow a demand that is patently unreasonable.

### Q14

#### ANSWER:

Best interests vary with the subject and the observer as well as the patient. The best interests have to be a judgement as to what a reasonable person with the patient's background and experience would want. The individual could perhaps be offered the same choice by at least two independent advocates working separately before making a judgement. In all cases knowledge of the patient is critical to any decision and it is clear that very rarely is there sufficient background information available at the point where it is most needed. More effort is needed to obtain personal data when patients are admitted to hospitals or into care homes

### Q16

#### ANSWER:

It must be assumed that the Welfare Attorney is fully aware of and has recorded evidence of the wishes of the patient and family, and is conversant with, or fully informed by medical professionals of the risks for the patient of any proposed healthcare. If that is the case then the Welfare Attorney should be the decider. However if a Doctor or Surgeon takes an Emergency decision intended to save

life, even though the outcome may prove unacceptable to a patient's interest then the decision ought not to be faulted. In many cases time will be of the essence, however there are cases when for example it has been proposed to move a patient from say a hospital or care home for the convenience of an organisation - the Welfare Attorneys view that such a move would prove dangerously traumatic to the patient should hold the action until tested in Court with independent expert witnesses

**Q17**

**ANSWER:**

Advance Directives are vital tools in decision making at the point where a patient is unable to make their preference known. Every person should be encouraged to make a directive to be lodged with their medical records.

**Q18**

**ANSWER:**

I have seen no evidence of the Act working in practice, and it is far from clear that professional bodies are more aware of their duties as a result. Indeed complaints still arise where proper concern for the dementia patient has failed.

**Q19**

**ANSWER:**

Yes. It is often necessary to minimise distress in the patient. e.g. "Is Mother coming to see me today?" (Mother died fifty years ago)"She'll be coming in later" is acceptable and the matter will pass for the time being. Circumstances at the time and the level of capacity determine the correct response.

**Q20**

**ANSWER:**

I feel that there is over caution in dealing with people with reduced capacity and this is as much due to over concern for the safety, convenience, or liability of the care staff, as it is for the safety and benefit of the patient. I would expect that the primary concern would always be for the patient using commonsense.

**Q21**

**ANSWER:**

Yes under exceptional circumstances to prevent self harm or harm to other persons. In many cases this may mean that the decision is instant and instinctive. Any case where this occurs should be followed up with higher levels of authority as soon as it is safe to do so, and the patient kept under constant medical supervision until further opinions are obtained. Wherever possible the need for restraint must be minimised by changing the situation under which the

challenge requiring restraint has arisen. The problem with any law is that it is a threat to the application of commonsense on the spot decisions for fear of legal action.

#### **Q22**

##### **ANSWER:**

Yes it is. Education however requires direct contact with people, who not only have an appreciation of ethical issues but have a detailed knowledge and practical experience of Dementia Care. Only by secondment under the guidance of an experienced Care Manager or Community Psychiatric Nurse will these skills be acquired.

#### **Q23**

##### **ANSWER:**

The matter of privacy, and the acceptability of risk taking, has to be weighed against the benefit of security and safety of any individual. The degree to which false alarms are given is a disadvantage. There must be concern that dependence upon Electronic technologies removes the need for regular personal contact with other people. This is especially the case for single persons living alone and who need more than an electronic link to keep them motivated.

#### **Q24**

##### **ANSWER:**

The state has accepted responsibility for care but has failed to treat everybody equally. It is unjust that state care is provided only to those whose income falls below arbitrary limits, particularly as those whose income is above the limits are not only paying for their own care but by taxation providing the state with the means to support the poorer. It is only those people who have a need for care that fall into this trap and the remainder of the population are not contributing, nor necessarily making provision for their own future care. The concept of an extension of National Insurance for all Health Care including long term dementia care makes sense ethically, but presumably would be seen by the bulk of taxpayers as an extra tax that does not yet benefit them.

#### **Q25**

##### **ANSWER:**

By taking time to discuss with the Carer their needs, expectations, possible outcomes and options. It may be that in some cases an independent advocate will be better placed to resolve conflicting emotions than a member of a health or adult services team.

#### **Q27**

**ANSWER:**

In general a couple(Carer and Caredfor)must be considered as a single unit in which every decision made about one has an effect upon the other. The health and wellbeing of a carer is as important as that of the cared for and no decisions should be made about an individual without full consultation and agreement by the Carer. If the health of a Care is so affected by their role that a Care Home placement is proposed then the wish of the Carer to be given additional/full time help in the home should drive the decision, alternatively both should be placed in the same care home.

**Q26****ANSWER:**

In principle these people should be should be fully informed about all the options available and have personal knowledge of the clients. This may not always be the case and the professionals may appear to press for a quick fix or one that reduces the cost and effort by their team. There is certainly a feeling that at times staff are being advised against making financial commitments

**Q28****ANSWER:**

In general Carers receive too little information. The state accepts that a Carer is the person who is primarily responsible for giving care; therefore that person must be entitled to full information and consultation about the Cared for. It is not necessary for a Carer to be present at every examination if the Cared for disagrees, but a separate consultation should then be available to the Carer.

**Q29****ANSWER:**

Noting that Dementia is not a discrete disease, then research cannot be focused solely on one issue. However since most cases arise through Alzheimer's then efforts should be concentrated on that disease, and funding allocated in proportion to the other dementias in proportion to their occurrence. In each case there appear to be three objectives-1. To be able to recognise the earliest indications of susceptibility e.g body chemistry, which will direct the attempts to find a cure, and by screening allow patients to make adjustments to their lives.2. To find a cure. 3. To develop methods of reducing the effects of the disease once it has developed e.g. speech therapy, psychological support programmes, incontinence, safe anti-psychotic treatment, safe anesthesia for surgery.

**Q30****ANSWER:**

No research should be permitted in which surgical or medical intervention is involved unless there is written evidence of agreement given by the patient when

they had capacity and that they had been fully informed of the possible risks.pain,side effects,benefit to themselves or others at that time. The decision to carry out research where there is written evidence of consent should be only with the consent of the next of kin.

**Q31**

**ANSWER:**

No comment

**Q32**

**ANSWER:**

It is unethical that patients who have dementia are less likely to receive mental and physical stimulation in hospitals and care homes, and they need specially adapted programmes to suit their incapacity.

**FEEDBACK:**

[No feedback]